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ABSTRACT

This primer on fetal alcohol syndrome (FAS) distinguishes between the syndrome and fetal alcohol effects (FAE), offers a history of FAS, outlines medical criteria for diagnosis, rates of incidence, factors influencing incidence and severity, developmental stages of children with FAS, clinical features, and educational implications and approaches. The primer points out that the single greatest block to the successful education of FAS/FAE students is the pervasive negative attitude surrounding these students due to the focus of research and media upon only the most severe minority of FAS/FAE students, which results in ignoring the identification and education of the less severely handicapped majority of FAS/FAE students. Contains 20 references and a list of 4 print resources. (JDD)

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The FAS Child: A Primer for Teachers

by

Thomas L. Wentz
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Julie Larson

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THE FAS CHILD: A PRIMER FOR TEACHERS

By Thomas L. Wentz and Julie Larson
Grand Forks, ND

It is not right that procreation should be the work
of bodies dissolved by excess wine, but rather that
the embryo should be compacted firmly, steadily,
and quietly in the womb.
Plato
427 -347 BC

INTRODUCTION

Life and education for millions of America's children have been compromised through intrauterine and environmental exposure to alcohol and other drugs. Today, fetal alcohol syndrome (FAS) is the leading known cause of mental retardation in the United States. Fetal alcohol syndrome is a set of three symptoms occurring together which constitute a prenatal birth defect caused by the consumption of alcohol during pregnancy. A less severe expression of the syndrome, fetal alcohol effects (FAE), requires one or two of the symptoms and includes even greater numbers of victims prenatally exposed to alcohol.

In order for the diagnosis of fetal alcohol syndrome to be made, a child must exhibit certain characteristics in each of three categories: growth (height and weight), neurological function, and head and facial characteristics. Fetal alcohol syndrome occurs along a continuum from severe to mild. When a child is deficient in only one or two of these areas and maternal alcohol abuse is confirmed, the term fetal alcohol effects (FAE) is preferred. FAE may occur in children of a woman who drinks lesser amounts of alcohol during pregnancy. No safe amount of alcohol has been found.

To help educators better understand FAS and its educational implications, this *Insights* article will address the following questions: What is FAS? How often does it occur? What are the causes and primary disabilities of FAS/FAE? What behaviors can be expected at each developmental stage? What are specific things teachers can do in the classroom? What should they know?

BACKGROUND

History

Although FAS and FAE are new, the conditions causing them are not. The first known writings of the effects of alcohol were in the Old Testament, Genesis 9:20; and the warnings against alcohol use during pregnancy, Judges 13:14, occurred approximately 1300 to 1000 BC. In 1834, a report to the British House of Commons said, "Infants of alcoholic mothers often have a starved, shriveled, and imperfect look" (Streissguth, LaDue, & Randels, 1988), and in 1968 a French physician, Dr. Paul Lamoine, reported a group of children born to alcoholic mothers who shared a set of abnormal features including retarded growth, abnormal faces, congenital malformations, and psychomotor disturbances (Smith & Eckardt, 1991). Then in 1973, Drs. Kenneth L. Jones and David W. Smith published clinical observations of 11 patients born to alcoholic mothers who all had similar patterns of malformations, growth deficiencies, and central nervous system abnormalities and coined the term "Fetal Alcohol Syndrome" (Streissguth et al., 1988).

Medical Criteria for Diagnosis

What is FAS? Fetal alcohol syndrome is now recognized as the number one cause of mental retardation in the United States and requires a medical diagnosis. A diagnosis of FAS, as recommended by the Research Society on Alcoholism (Steinhausen, Willms, & Spohr, 1993), requires confirmation of alcohol abuse by the mother and the following criteria: (1) pre- or postnatal growth retardation (height and weight below the 10th percentile for age or gestational age); (2) Central Nervous System (CNS) dysfunction (any neurological abnormality, developmental delay, or intellectual impairment); and (3) characteristic head and facial abnormalities, including small head circumference (below the 3rd percentile), microphthalmia or short palpebral fissures, poorly developed philtrum, thin upper lip, and flattening of the maxillary area. Fetal alcohol effects (FAE) requires, for diagnosis, two of the three criteria (Steinhausen et al., 1993).

It is important to note a diagnosis of FAS/FAE in and of itself does not access Special Education services. In order to receive services it is necessary to document a loss of learning and demonstrate a condition which interferes with learning.

Rates of Incidence

How often does it occur? Conservatively, in the U.S. approximately 2 in every 1000 children are born with fetal alcohol syndrome and 1 in 300 to 350 children is born with fetal alcohol effects (Streissguth & Burgess, 1992). These figures are conservative, and the incidence of FAS and FAE reflects "only those children who have actually been identified." In other words, across the world doctors have reported rates of FAS from .4 to 3.1 per thousand births (Abel, 1984), while the rate of FAE, which is much more difficult to assess, runs 3 to 4 times higher (Abel & Sokol, 1987). However, contrary to Abel and Sokol's (1987) national research, Burd (1993) has found the incidence of FAE to be 6 to 10 times higher than FAS in North Dakota. If this rate holds for more current studies at the national level, rates of FAE may be much higher than previously thought.

Factors Influencing Rates of Incidence and Severity

What are the causes and primary disabilities of FAS/FAE? Although FAS is an outcome of heavy drinking throughout pregnancy and is associated with chronic maternal alcoholism (Hanson, Streissguth, & Smith, 1978; Jones & Smith, 1973; Streissguth, Barr, & Sampson, 1990; Streissguth, Clarren, & Jones, 1985), FAE is associated with social and binge drinking among pregnant women (Streissguth et al., 1990).

Children exposed to one ounce of alcohol per day during midpregnancy had "significantly lower IQ than children not exposed to alcohol during pregnancy" (Streissguth et al., 1990). Maternal consumption of over three drinks per day in early pregnancy was estimated to triple the risk of subnormal IQ (Smith & Eckardt, 1991). Binge drinking, which also contributed to the lowered IQ in offspring, was considered to be five or more drinks in any one day (Streissguth et al., 1990).

According to Dr. K. L. Jones in *Pediatric Rounds* (1993),

> *In a study of mental development in 1-year-old babies born to "professional" women, a significant linear relationship was found between drinking patterns prior to pregnancy recognition and mental development of the offspring . . . Because maternal IQ score and infant development are usually highly correlated, the 24 point differences in the babies born to women who drank 1.0 oz. of absolute alcohol per day suggests a deleterious effect of moderate alcohol consumption on mental development. (p. 7)*

Streissguth et al. (1990) report that maternal alcoholism, binge, and social drinking across all socioeconomic lines result in a reduced IQ; the mean IQ for children with FAS/FAE is approximately 70. The

intelligence of a particular child may vary. Some of these children are not mentally retarded but many display learning disabilities (Streissguth et al., 1990), behavioral problems (especially hyperactivity [Streissguth et al., 1988]), and attention deficits (Nanson & Hiscock, 1990), as well as long-term psychopathologies (Steinhausen et al., 1993).

Developmental Stages

What are the effects of maternal drinking upon the fetus? Fetal alcohol syndrome affects the fetus in three ways: growth retardation, dysmorphic facial features, and mental retardation. The severity of these features is positively correlated to the degree of maternal drinking (Graham, Hanson, Darby, Barr, & Streissguth, 1988) and the stage of maternal alcoholism (Ernhart, Wolf, Linn, Sokol, Kennard, & Filipovich, 1985; Majewski, 1981).

At the time of birth, the baby's length, weight, and head circumference are at less than the 3rd percentile (Streissguth et al., 1985). The disturbances in the Central Nervous System (CNS) are present before birth rather than as any postnatal environmental impact and are predictive in terms of later outcomes (Smith & Eckardt, 1991), particularly of developmental delays, lowered IQ, and long-term psychopathology (Steinhausen et al., 1993).

Ann Streissguth et al. (1988) had the following observations concerning developmental stages based upon their research.

Infancy. The most distinguishing characteristic of FAS infants is their small, scrawny appearance. Oftentimes these babies are irritable, tremulous, display a weak sucking reflex, weak muscle tone (hypotonia), and continue to lose weight longer after birth than is usual (failure to thrive). Continued hospitalization and subsequent readmissions for failure to thrive, pneumonia, heart defects, and hip dysplasia are common. Feeding difficulties and erratic sleep patterns confront both the infant and the caretakers. These babies are slow to master motor milestones, slow to say and combine words, yet behaviorally are often described as "very good."

Preschool years. At this age children with FAS are usually small in stature, appearing "elf-like" with "butterfly-like" movements. Small size is often the excuse used for their slow development and poor performance. "Oh, he'll outgrow it" is a common statement, and developmental delays are not always taken seriously. Seemingly alert, these children are excessively friendly and more interested in people than in objects. Their need for bodily contact seems insatiable. They may begin talking, but expressive speech may be delayed. Talking a lot, with numerous questions, gives the superficial appearance that speech is not impaired in spite of the lack of richness and grammatical complexity. Hyperactivity is most pronounced at this age. FAS children experience poor coordination and problems with fine and gross motor control which become apparent when learning to draw, color, or ride tricycles.

Early school years. Delays in starting school, or retention in kindergarten with the hope that motor skills will develop and hyperactivity will disappear, are common. Special education referrals for the most obviously mentally handicapped occur, while less handicapped FAS children continue in regular education classrooms.

Difficulties begin to appear as demands for classroom attention increase. Short attention span, emotional instability, poor impulse control, memory deficits, and social intrusiveness emerge. In more functional children, poor peer relations and social isolation may be observed. Hostility and destructiveness sometimes appear but may be more related to the home environment than school.

Middle school years. School achievement hits a maximum level at the middle school years, with reading and spelling being better than arithmetic skills. A convergence

occurs between increased classroom demands to maintain attention, complete assignments, and master new academic skills, with the resulting stress. This, in turn, leads to poor school motivation, poor performance, and later truancy and school dropout. Evaluation and special education placement usually occur even for the most functional of children. However, good verbal skills, a social personality, and good intentions tend to continue to hide the seriousness of the handicap for many others.

Adolescents. In adolescence, the shortness in height tends to remain, and weight approaches normal standards, with FAS adolescents shorter and lighter in weight than FAE adolescents. IQ averages in Streisguth's (1988) study were 68 with a range of 20 to 102. Generally, adolescents with FAS tended to be lower functioning than those with FAE.

Academic achievement tends to peak out in later elementary school, grades 6-8, and at about ages 12 to 15, for both FAS and FAE victims. Transitions to middle school and then to high school pose problems for adolescents with both categories of the syndrome. Generalizing knowledge and doing higher level abstractions for reading comprehension and math are difficult. These students have difficulty staying on task, distract other students, express poor language, are unable to structure work time, and require constant monitoring and attention. Stubbornness, immaturity, poor self-image, poor social attitude, and difficulty dealing with change are all challenges faced daily by FAS/FAE adolescents.

Behaviorally, FAS/FAE adolescents exhibit impulsivity, poor judgment, naiveté, and lack inhibition. An excess of friendliness at this age presents exploitative circumstances in all areas of life. This previously mentioned characteristic is coupled with difficulty making friends and results in social isolation.

Overall, the prognosis is not favorable. Higher risks for depression and anxiety, alcohol and drug abuse, coupled with the previously mentioned limitations, present a lifetime of compromise. Unable to maintain employment, continue relationships, adapt to change, or master the most basic of skills, FAS/FAE adolescents and young adults tend to become transients, lost in their own lives.

Clinical Features of FAS

About what other characteristics should we know? In addition to the above, other abnormalities are associated with fetal alcohol syndrome. They include joint and limb malformation, cardiac abnormalities, and kidney disorders (Streissguth et al., 1985). Studies also indicate speech disorders and verbal delays (Becker, Warr-Leeper, & Leeper, 1990) in children with FAS.

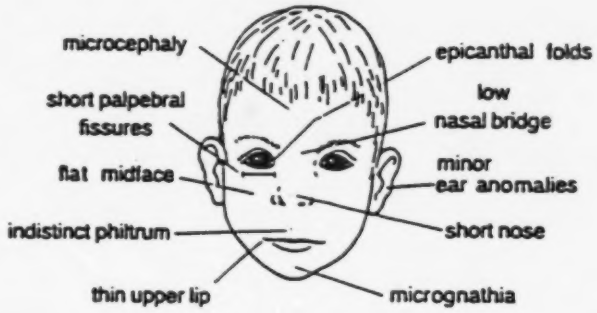
Prenatal and postnatal growth deficiencies in height, weight, and head circumference are the most common physical characteristics. Affected children continue to be smaller than their peers. Low birthweight is an area of concern. Studies have shown the severity of weight loss is related to the volume of alcohol consumed by the mother during pregnancy (Ernhart, 1991). As alcohol exposure increases in volume, the severity of low birthweight increases, particularly if drinking occurs during the first trimester when the effects of alcohol on overall growth are most apparent (Ernhart, 1991).

One of the most common characteristics seen in children with FAS is microcephaly or disproportionally small head size. The size of a head increases during pregnancy to accommodate the growing brain. Therefore, reduced head size is usually indicative of a smaller brain—a feature commonly associated with mental retardation. In humans, the brain undergoes two growth spurts. It is during these times that the brain is most sensitive to alcohol exposure. Overall, physically and mentally, these affected children seldom, if ever, "catch up" even when provided with good nutrition.

There are some facial features which seem to occur with enough frequency to be considered typical in children with FAS. It is, however, important to remember that the

combination of a variety of facial characteristics (see inset below), not the presence of any one or two individual features, must be taken into account when making a diagnosis. It is also important to note that dysmorphologists, even after years of experience, do not report the diagnosis of FAS without the confirmation of maternal alcohol use during pregnancy.

FACIES IN FETAL ALCOHOL SYNDROME



Educational Implications and Approaches

What can teachers do to help? Educators should note that learning disabilities and behavioral problems not originally associated with FAS/FAE may sometimes later be attributed to the effects of alcohol. Often these disabilities do not surface until later in childhood or when the child begins school. Children commonly show one or more characteristics such as hyperactivity, inability to concentrate, impaired ability to block out distractions or stimuli, delayed verbal skills, and reduced cognitive and perceptual skills which do not become apparent until the increasing demands of school have frustrated the affected children.

The teacher may find that providing the optimal educational program is a challenge. It is difficult to come up with a specific curriculum for FAS/FAE students because each child is so unique and can be erratic in behavior and learning abilities. However, experience has shown us there are things teachers can do. The following suggestions may be helpful:

1. The less stimulation and the more one-on-one contact the better.
2. FAS/FAE children need routine consistency and positive discipline.
3. It is important to be very concrete with FAS/FAE children.
4. It is important to use visual aids, manipulatives, and physical activity.
5. Concepts must be repeated over and over; what is taught one day may not be remembered the next day. FAS/FAE children seem to be continually "starting over" or "starting from scratch" on schoolwork or homework. They know that last week they learned something and may have understood but are at a loss to reconstruct the learning for themselves.
6. FAS/FAE children are hypersensitive to criticism.
7. FAS/FAE children have a difficult time following through with a task.
8. School-age children and adolescents are schedule dependent and have difficulty adapting to unexpected schedule changes.
9. FAS/FAE children have difficulty transferring information from one situation to another.
10. FAS/FAE students have trouble with verbal instructions; even when it is apparent they have heard what was spoken they may appear to have understood more than they actually did. They will look, attend, and still remain confused or unclear about directions.
11. A major focus of educators should be effective communication. Just as there is a wide range of IQ and achievement among those with FAS/FAE, so is there

great variability in communication skills. Their language skills often appear greater than their ability to comprehend and communicate effectively. Much acting-out behavior occurs because of their frustrations to adequately express themselves.

12. Communication skills should be developed in the context of social skills instruction because the two are inseparable. Communication and social skills are essential to live and work in the school and community and necessitate being major components of the education process.

13. It is critical to remember that FAS/FAE children and adolescents need empathy, acceptance, patience, guidance, and acknowledgment for all they can do.

14. The focus of education and curriculum must move from academic skills to functional and vocational skills which take place in the related environment and require being "community based."

15. Perhaps the most important question we educators must ask ourselves is "What do we need to teach FAS/FAE children to get along in society?" We need to ask "Is what we are teaching relevant?" Next, we need to reframe our expectations, and we need to work with affected children at their educational level.

Conclusion

Fetal alcohol syndrome/fetal alcohol effects are irreversible birth defects that are completely preventable. FAS/FAE are caused by mothers using alcohol, from chronic alcoholism to social drinking. Alcohol has been medically proven to interfere with the normal growth of the fetus at all levels, beginning prior to organogenesis (cellular specification for organ formation), throughout gestation, and continuing through any breastfeeding time thereafter. Alcohol primarily insults the fetus through mental retardation, physical malformations, and growth deficiencies, all in varying degrees of severity related to the volume of alcohol consumed and the timing of gestational development.

At the present time, the only "experts" in the field of education are those teachers who work with FAS/FAE children on a daily basis. Many teachers directly involved with the intervention and treatment have developed strategies for their own classrooms but have not had the opportunities to share their approaches. Other teachers have documented their hard learned lessons and are sharing those strategies as best they can (for a brief list see section marked RESOURCES and MATERIALS). However, most approaches and strategies developed by teachers lack a research base that needs to be established before wholesale application can take place. Much more needs to be done to assist both teachers and FAS/FAE students.

As teachers are aware, there are many impediments to the successful teaching of FAS/FAE students. Perhaps the single greatest block to the successful education of FAS/FAE students is the pervasive negative attitude surrounding these students. As a result of research and media focus upon only the most severe (and minority) of FAS/FAE students, the identification and education of the less severely handicapped (and majority) of FAS/FAE students have been ignored. In this manner, some researchers have also ignored studying the solutions to teachers' and students' dilemmas, in short, the "how to" of teaching.

The fact is, FAS/FAE students have always been in the schools; some have been successfully educated and some have not. What we have today are much greater numbers of students whose lives have been compromised by alcohol and other drugs than in the past. And, until the other "experts" catch up with the more immediate and compelling needs of teachers and the students with FAS/FAE, teachers will continue to teach and ask those two, time honored questions: (1) Is it good for students? and (2) Is it working for students?

GLOSSARY OF TERMS

Binge Drinking: In studies of FAS/FAE the consecutive drinking of five or more drinks in any one episode. Also, an intensive but circumscribed period of drinking extending over days or several weeks.

Central Nervous System (CNS): That part which consists of the brain (forebrain, midbrain, and hindbrain) and is developed from the anterior part of the embryonic neural tube; the brainstem consisting of the connection between the cerebral hemispheres and the spinal cord.

Dysmorphic: Abnormal development of form and structure; in FAS children particularly the head, eyes, nose, philtrum, upper lip, ears, skeletal, and cardiac.

Epicanthal Folds: The fold of skin in the corners of the eyes.

Maxillary Areas: Areas of the jaw that contain the teeth.

Micrognathia: Small chin.

Microphthalmia: Abnormal smallness of the eyeball.

Palpebral Fissures: Small longitudinal opening between the eyelids.

Philtrum: The vertical groove in the median portion of the upper lip.

RESOURCES AND MATERIALS

Publications and Materials

A systemic approach to dealing with fetal alcohol and other drug affected children in an educational setting, participant workbook. (1991). From the Western Regional Center Drug-Free Schools and Communities Project:
Northwest Regional Education Laboratory
101 S.W. Main Street, Suite 500
Portland, OR 97204
1-800-547-6339

A manual on adolescents and adults with fetal alcohol syndrome with special reference to American Indians. (1988). 2nd ed. A. Streissguth, R. A. LaDue, and S. P. Randels:
U.S. Dept. of Health and Human Services
Indian Health Service
Rockville, MD

The broken cord: A family's ongoing struggle with fetal alcohol syndrome. (1989). Michael Dorris. New York: Harper & Row.

Fetal alcohol syndrome manual:
Early Childhood Research Project
South Dakota Univ. Affiliated Programs
USD School of Medicine
208 Julian Hall
Vermillion, SD 57069
1-800-658-3080 (TDD/Voice) or
(605) 677-5311

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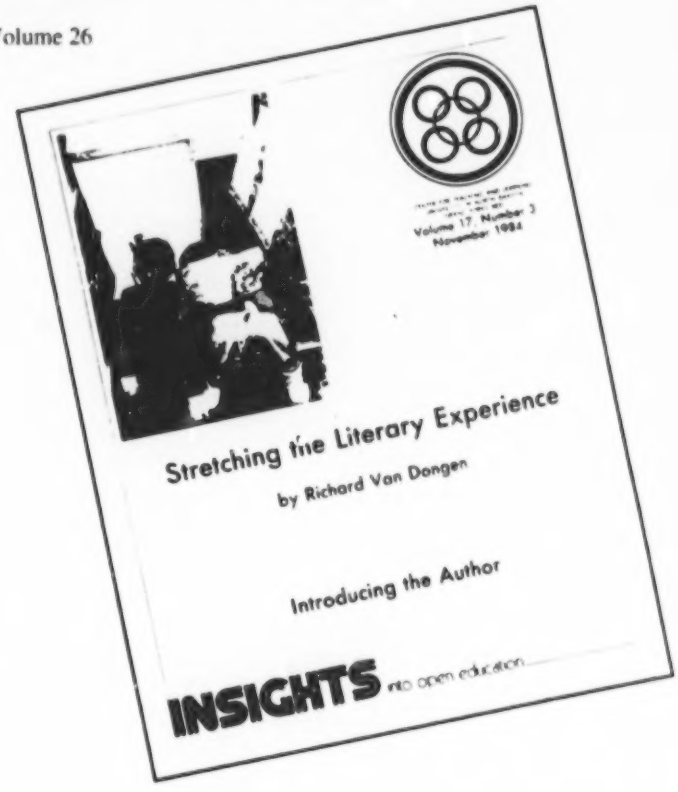

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